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ILLNESS STORIES:
FROM RECOGNIZING THE SIGNIFICANCE IN
CARE TO PLANNING MY OWN STORIED PRACTICE

A Synthesis Project Presented

by

JANE A. LACHANCE

Submitted to the Office of Graduate Studies, University of Massachusetts Boston

Master of Arts

December, 2007

Critical and Creative Thinking Program

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ABSTRACT

ILLNESS STORIES: FROM RECOGNIZING THE SIGNIFICANCE IN CARE TO PLANNING MY OWN STORIED PRACTICE

December 2007

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In this paper, stories of illness are identified as belonging to a specific genre of story that represents an ill person's interpretation of experience and hence the meaning(s) of illness. The ill person is recognized as member of a family embedded in a social setting with cultural mores that contribute to experience and meanings. The meaning of illness is significant because it affects the care of illness. This paper focuses on chronic illness, an illness without cure that is managed over a lifetime and is characterized by remission and exacerbation of symptoms. Our current bio-medical health care system reframes the illness to disease, reduces it to pathology and misses the meaning for patients. Conflict and noncompliance result. What I am calling a storied approach complements current care and management of chronic illness by improving patient care, and the management of illness and by encouraging collaborative care.

We organize experience and make sense of things by telling our stories. Jerome Bruner characterizes narrative knowing based on storytelling as a way to construct reality and understand human behavior. The conception of illness story is based on the work of Arthur Kleinman, who has studied chronic illness meaning(s), and describes a supporting framework that includes symptom meaning, cultural input and personal/social meaning and explanatory models. Stories change over time and circumstance; the meaning of illness experience changes. Two research studies are presented to identify factors that influence change from loss to mastery.

The story of my nursing practice in case management has significantly changed over time with new skills, knowledge and experience acquired in the Critical and Creative Thinking Program. I briefly describe my progress at the beginning of each chapter. I propose a reorientation of my nursing practice as well as next steps to take in my journey. Two illness stories are included in the appendix: Donna's story and Lisa's story provide examples of illness stories encountered during my graduate study.

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INTRODUCTION

Our experience with the onset of an illness, the ongoing management of illness, and the impact illness has on our relationships is the stuff of stories. “It all started with ...” begins the story. In fact, stories of illness help us to make sense of the illness experience and interpret the experience as meaningful. As a nurse, I have elicited, listened to and told lots of stories over many years. Although I loved hearing those stories; I was motivated, inspired, enlightened and entertained by them, I didn’t recognize the significance of stories told from someone’s experience of illness, the relationship of an illness story to the care and management of illness or its contribution to well being.

My exploration of story took place in and was guided by the Critical and Creative Thinking Program, which I had accidentally stumbled into one spring semester. New thinking skills, problem solving strategies and beginning reflective practice motivated me to explore story in the context of health care and challenge my long standing beliefs and values shaped by education and practice within traditional western medicine. For example, I believed that the physician directed care and that the diagnosis directed treatment which was effective for everyone, a “one size fits all” approach. I valued biological investigations without thought to cultural context. I had difficulty understanding and accepting patient noncompliance with treatment/management of chronic illness. Around this time, I discovered an emerging interest in the use of story in healthcare as well as evidence to support the benefits of its use. At the same time, I was increasingly frustrated with my nursing role as a case manager, with responsibilities that include utilization review, quality assessment and discharge planning, in a small

community hospital. I needed to make a change but felt uncertain about direction. I wondered about leaving the nursing profession altogether. As I continued my personal and professional growth in the Critical and Creative Thinking Program, I came to see an alternative to exodus. I began to use story in my daily practice.

I practiced telling stories to facilitate patient care. I shared patient stories with other patients to provide examples of discharge planning options. I shared stories to widen patient/family perspectives and to provide support. I became more aware of my assumptions and biases around my nursing practice, such as that health care providers know best and that repeated hospitalizations for patients with chronic illness are likely a result of patient noncompliance with prescribed treatment. As I increased my awareness, I improved my skills so that I began to really listen to patient stories. My communication with patients and families improved and helped to establish mutually agreed upon hospital discharge plans. In spite of my increasing awareness and use of story in my daily practice, I continued to feel disheartened by the hospital environment. It was always rushed and sometimes chaotic. There was a lack of communication and/or miscommunication among staff, patients and families. Patient care was fragmented and limited resources were used ineffectively. There was never enough time to get the whole story.

I paused to reflect on my values, beliefs and interests. I recognized my increasing ability to take risks. I experienced an illuminating moment during an otherwise routine drive home not long ago. I suddenly saw the solution: create my own storied case management practice outside the institutional walls. In order to step out, I need to broaden my understanding of the individual's story of illness that represents the meaning

of illness and its relationship to an individual's care. My synthesis project is about movement, from recognizing the significance of illness stories in health care to planning my own storied practice. I propose to identify illness stories specific to chronic illness, explore the process of illness story construction and relationship to care, identify factors involved with changing story, review the benefits of a storied approach in health care, and outline my plans for the future.

The making of a story and its telling provide a way of knowing, a way of organizing experience and constructing our reality. Psychologist Jerome Bruner posited two modes of thought that are distinguished by the way they interpret experience. (Bruner, 1986; McAdams, 2006) One way of knowing is logical-scientific; it is rational, based on cause and effect, directed by hypothesis and empirical evidence in pursuit of causal truth. For example, scientific principles are based on logical-scientific knowing. In Donna's story, "Going to The Well," (Appendix 1) she knows the diagnosis of chronic lymphocytic lymphoma because it is based on the pathology of blood studies. It is true. In contrast, narrative knowing is imaginative, based on story telling describing human activity, with actions, thought and emotions integrated by cultural context and organized over time. Narrative knowing seeks understanding of human behavior, intension, motivation and passion. Donna's story (Appendix 1) illustrates how she acts based on beliefs and desires in a specific socio-cultural setting. For example, the pursuit of alternative health care strategies like acupuncture is part of the local culture that guides her action. Her story not only helps her to begin to understand her diagnosis but it helps us as listeners to understand and connect with her experience. It is authentic. Bruner

says a good story convinces us of lifelikeness and has “no need for testability” in contrast to conclusive evidence required in logical-scientific knowing. (Bruner, 1986, p.14)

Narrative knowing is reflected in the work of Dr Arthur Kleinman whose theory of illness, based on clinical experience studying patients’ experience of illness, conveys a strong message that illness has meaning and is represented in patient stories as well as in the stories of their friends and family integrated by socio-cultural mores. Meaning is significant because it not only reflects an individual’s interpretation but also directs behavior, attitude and expectations. Therefore, meaning impacts the care and management of someone’s illness. He argues that the skills required for recognition and interpretation of the illness stories have “atrophied in biomedical training” and are, in fact, essential to improving care of chronic illness and humanizing our current bio-medical care model. (Kleinman, 1988, p. xiv)

Stories of illness become embedded in life stories. Dan McAdams is a narrative psychologist who explores the relationship between lives lived and stories told. He identifies a uniquely American story called “the redemptive self” told by midlife adults who are committed to make a difference by passing knowledge, skills and talents to the next generation. He uses this example to argue that stories reflect personal identity as well as support a coherent and unified life story. This provides an additional perspective on illness story construction. (McAdams, 2006)

Chapter One briefly explores story landscape: the nature of story, the truth of story and examples of the benefits of stories used in health care. A classmate once asked me just what I meant by story, which motivated me to identify its basic structure and distinguishing parts: an account characterized by emotional tone and perceptual imagery.

Since many adults associate story with children and fairy tales, a brief description is essential to the project. In addition, the truth of the story is significant since patients' perceptions can be easily discounted if perceptions don't reflect objective data. The use of story in nursing and examples of health benefits are described.

Chapter Two focuses on illness stories in chronic illness. Chronic illness and its prevalence is briefly discussed, as well as illness story/levels of meaning as described by Kleinman, impact on care and management, the bio-medical model /disease story and conflicting stories. Jacqui's story is taken from my experience at work and illustrates the problems arising from conflicting stories. Some illness is brief; evaluation and management take place, recovery is complete and disruption to life is minimal. In contrast, chronic illness takes place over a lifetime and is embedded in someone's life. Chronic illness is the type of illness and experience of illness that concerns me for this project. The construction and development of an illness story depends on biography, relationships and socio-cultural cues over time. The story represents the meaning(s) of the illness experience at a particular time and impacts care and management. For example, I recently met an engaging elderly man recovering from surgery to repair an incisional hernia. He also suffered with rheumatoid arthritis, body joints swollen and gnarled, but he managed well at home. I wanted to arrange for the hospital physical therapist to evaluate his ability to be up and about since the patient hadn't been up and walking to date. As I inquired about his surgery and listened to his story, to my surprise I heard him say that a physical therapist at home had "caused my hernia". Not surprisingly, he was reluctant to work with a physical therapist in the hospital.

Chapter Three explores meaning shifts with identification of themes and a model that offers additional analysis of the movement of stories in illness: what motivates us to change our story? Stories hold the meaning of experience at a certain point in time and change over time and with circumstances. The construction and reconstruction of stories is a dynamic process. There are meaning shift themes and models to provide further understanding that are discussed in research studies with titles like “Meaning Shift: Findings from Wellness Acupuncture” and “Story making and Storytelling: Making Sense of Living with Multiple Sclerosis.” The relationship between teller and listener is one determinant that can facilitate a meaning shift and reconstruction of an illness story. The benefits for story teller and story listener include increased awareness, insight and understanding for both.

Chapter Four identifies implications for my nursing practice, which will be distinguished by story. I have long used the metaphor of tour guide for my case management practice, since I imagine myself as guiding patient tours along the continuum of health care, helping patients to navigate a confusing and complex system of care. It’s fitting to name my private practice “Tour Guides for Health.” Although the business plan for stepping out is beyond the scope of this project, the concept is discussed with a preliminary mission statement. Another long term project is presented: co-hosting a radio talk show. Imagine callers with questions and problems around health care access issues, for example, “I live out of state and when I visit my mother she demonstrates forgetfulness and some confusion...refusing help at home...what can I do?” An educational workshop about stories of illness and implications for care directed toward nursing conducted in the setting of the League for Advancement of New England

Storytelling annual conference (LANES) is outlined. I conclude with reflections on my experience, my personal/professional growth and development and my sense of renewal and hopefulness.

There are two examples of illness stories in the Appendix. While I was learning about stories of illness, I learned that my best friend was diagnosed with a chronic illness and was in the process of making sense of her illness. She was constructing her own story. As her long time friend, I have a part in her story and contribute to her experience. I set out to observe, watch, listen, and receive her story. I wrote my interpretation of Donna's experience/story of illness that is based on taped interviews and a whirlwind trip to Santa Fe. The second story belongs to my sister Lisa who lives in Montana and was diagnosed with Multiple Sclerosis during my Critical and Creative Thinking journey. I first suggested that she write down and tell her story about a year ago. It wasn't until November of this year that she announced her story was written down and told. As she reflected on the process, she described it as helpful to "piece it together...understand what was happening to me...how to face it...how to manage it...make sense of it all."

CHAPTER 1

THE STORY SCENE

Stories are familiar to all of us: childhood stories, classic fairy tales and family stories passed along generations. I never tire of hearing the story of how my grandmother's family left Ireland late one night, traveled to the coast and sailed to this country in the early twentieth century. Family stories connect us to our ancestral heritage, and increase our self-awareness and sense of community. Fairy tales have existed for thousands of years and up until two hundred years ago were told to adults as well as children. (Von Franz, 1996, p. 4) The symbolic language and vivid imagery of fairy tales represent meaning that can help with problem solving, foster development of intellect and facilitate healing even without conscious interpretation. Fairy tale imagery "speaks beneath the knowing consciousness." (Dieckman, 1986, p. 28) Dr Naomi Remen describes telling stories around her family's kitchen table and calls it a "level playing field" where all members' stories matter as means to pass along instruction, inspiration and understanding. "Everybody is a story." (Remen, 1995, p. xxvii) Our lives are made up of a series of stories, stories about who we are our relationships to others and our place in community.

Jerome Bruner, a recognized authority on the subject of stories in human lives, proposes narrative knowing as an ordering of experience and construction of reality. Narrative knowing is characterized by story in order to understand the meaning of human behavior. Stories are about human conduct, character's desires, intentions, actions and consequences as well as a plan to carry these out that takes place over time.

Thoughts and feelings or consciousness and action are brought together in a socio-cultural specific setting that direct the process of creating a story or narrative.

According to Bruner, this story or narrative offers a way to order the experience which then shapes our action and constructs our reality. The story plot depends on changing consciousness and action or circumstance. Since the consciousness and action world are joined by specific cultural settings, the meaning of experience reflects personal understanding and expectations gained from participating in the specific socio-cultural domain. He notes that stories are generally told when there is a deviation from the usual cultural norm such as danger, threat or challenge. (Bruner, 1986; Mattingly & Garo, 2000; McAdams, 2006). The disruption of illness poses a challenge that alters consciousness and action in the context of a specific socio-cultural setting that gives rise to the process and act of storytelling, listening and interpreting as a way to give meaning to experience.

When we seek understanding about human behavior such as motivation, desire, intention and overcoming obstacles over time, we look toward narrative or story. Bruner believes that humans evolved to be story tellers and that story telling proved to be a successful adaptive practice in the social life of the past. This would help to explain why story telling is present in all cultures. The evolutionary aspect of story telling is interesting because episodic memory is a memory subsystem that has more recently evolved. Episodic memory is obtained by the use of cognition, represented by information regarding the relationship between a person and an event and expressed in various behavior forms. (Tulving, 1985) It makes it possible to go back in time and remember past experience that we call upon for story telling.

In addition to Bruner's narrative mode of thinking, there is a range of disciplines that offer narrative analysis such as literary, linguistic and cognitive disciplines. Although each offers a particular spin on the relationship between structure and content, there are common elements that make up the nature of story. There is some agreement that story has a temporal order, a beginning, a middle and an ending, with a unified plot containing character, dilemma and a resolution of sorts. It is distinguished by emotional tone, perceptual imagery and engagement with the listener. There is an acute sense of, "and then what", and "what happened next?" A story is unified, cohesive and coherent and reflects the prevailing cultural convention. The generalized nature of story reflects Bruner's components of thought. (Paley and Eva, 2005; Sandelowski, 1994; Bowles, 1995)

Although there is some agreement about story definition and structure, the emotional tone of the story is problematic for some. The truth of personal experience is analyzed by Paley and Eva who examine stories in health care. (Paley & Eva, 2005) Although "narrative" and "story" are used interchangeably in this project, they distinguish between narrative and story by describing narrative as a report, "what happened", a sequence of events with causal connections. They define story, on the other hand, as an evolved narrative characterized by character, plot and an emotional cadence. There is a sense of "how it seems to me", rather than "how it was". The authors argue that story and narrative must be recognized separately in order to avoid confusion between the emotional tone of the story and the objective account of the narrative. They go on to suggest that a story of illness, for example, may be emotionally persuasive but lacking

credibility. Patient stories can be mistaken, insincere and “beside the point.” (Paley and Eva 2005, p. 85)

This reminds me of a story of an elderly woman who was hospitalized for the treatment of severe respiratory illness. She minced no words about her desire to get home and resume cigarette smoking. Upon further dialogue, she admitted to a fear of dying if she stopped smoking! Although her story is based on “mistaken” and an incredible premise, she had constructed this story based on her interpretation of the death of two close friends who had recently quit smoking. It made sense to her. Paley and Eva warn against “romanticizing narrative,” asserting that the accompanying emotional response to story may detract or be mistaken for reality. (Paley & Eva, 2005) On the contrary, the emotional aspect of story is integral to its makeup and must be recognized to understand the story or meaning of experience for someone. The meaning of smoking cessation for the woman eager to go home and “light up” requires further inquiry. Rather than dismiss her interpretation as absurd, manipulative or denial, her story can be elicited to find the meaning of cessation that seems embedded in her friends’ death. The inner landscape or “how it seems to me” influences action to construct the story/ narrative knowing. Although Bruner describes a “good story” as one that is convincing or plausible, it does not need “testability.” (Bruner, 1986, p. 12)

James Pennebaker is a psychologist who investigated personal story with an emphasis on emotional aspect. He conducted a series of interesting experiments over a decade. The data support specific health benefits of story. For example, he discovered that when people who had suffered significant trauma constructed a story about their experience, they demonstrated improved physical and mental health. The experiment

went like this: participating college students were told that they would be writing about an assigned topic for fifteen minutes every day for four days. The experiment group was instructed to write about a personal trauma with emphasis on exploring deepest thoughts, feelings and impact on relationships. The control group wrote about non- emotional topics like describing the laboratory room. Six months later, all the students provided specific health information. The experiment group demonstrated improved health benefits that included a reduction in illness requiring physician visits, positive blood markers in the immune system and an altered emotional status around the traumatic event. Participants described a sense of “moving on.” The results were duplicated in later studies that compared writing with talking. (Pennebaker, 2000)

Pennebaker’s work illustrates the health benefits of story. The act of telling the story leads to a reduction of the physiological work required to inhibit thoughts and feelings around the traumatic event. It takes significant effort and energy to hold back strong, particularly negative, emotions. The physiology of this work includes increased heart rate, increased blood pressure and hormonal changes that over time can lead to stress related illnesses like infections and ulcers. Telling the story acts as a stress management tool.

How does this stand the test of time? Pennebaker notes there is little evidence to support the view that the telling alone leads to long lasting changes in behavior. In order to explore this, he developed a computer program that measured emotional and cognitive categories to further analyze the students’ essays. He investigated the use of negative and positive emotion words. The more frequent use of positive-emotion words, the more improved health. Moderate use of negative-emotion words also showed improved health

during the study. Students whose negative-emotion was either low, characterized by difficulty with naming an emotion, or high, characterized by repeated complaining, showed no improved health benefits. According to Pennebaker, they seemed unable to obtain closure to their traumatic experience. He suggests that inability to obtain closure is exacerbated by an inability to construct their story. (Pennebaker, 2000)

Another health benefit to telling the story is an increase in insight and understanding. After he completed analysis of emotional categories in the students' essays, Pennebaker evaluated cognitive word categories in their essays. The data showed an increase in student insight and understanding as their story developed over time. With additional experience, information and new perspective, the story changes over time. He concludes that the "act of constructing stories is associated with mental and physical health improvement. A constructed story then is a kind of knowledge that helps organize the emotional effects of an experience as well as the experience itself." (Pennebaker, 2000, p. 6)

This kind of knowledge, organizing and understanding, is also identified by Dr Mollica of Massachusetts General Hospital, who has cared for victims of extreme trauma during the past twenty five years. His patients have experienced violence, torture, deprivation and nearly unimaginable acts of brutality. He discovered that their stories of trauma become stories of healing and survival over time. Many are from foreign cultures and at first glance the images of some stories seem nonsensical, like this excerpt from a Cambodian woman who survived the Khmer Rouge labor camps. She was one of the first patients to seek help at Dr Mollica's new clinic. Her story begins, "During the year of the snake, the god of the sun came to stay in my body. It made my body shaky all

over-and I fainted.” (Mollica, 2007) Dr Mollica is quick to point out that the woman’s story seemed beyond reality with references to possession by the god of the sun, but in fact she was describing her experience as dreams that reflect a healing journey in the context of her Buddhist religion. Dr Mollica believes that self-healing is a natural human response to psychological illness and injury that requires a reconstruction of self and community. The act of converting emotions and images into words changes the way a person thinks about the trauma. Telling the story is one of the elements in recovery and reconstructing self to participate in community.

Personal stories may vary in structure but all possess a distinct emotional tone. Stories can’t be precisely measured against objective criteria but do represent meaning, making sense of something, gaining understanding or insight into an experience. We make sense of our lives by the stories we construct and those stories tell us who we are. Our stories change with interpretation of experiences and circumstances over time so that our stories are a representation of life at a certain time. We tell our stories, revise them and tell them again, working toward a narrative identify or “coherent self” as described by McAdams. (McAdams,2006).Our narrative self construction takes place in the context of relationship, social and cultural mores.

McAdams explores a kind of personal narrative, specific themed story that he describes as a redemption story that is characteristic of people termed “generative adults.” Generativity is a psychological term reflecting Erikson’s human development theory and life stages specifically around the developmental task of isolation versus generativity that takes place in adulthood to old age. Generative adults are people who are concerned about the wellbeing of future generations and contribute by passing on

skill, knowledge, talent and service to the next generation. According to McAdams' research, generative adults construct a story that is characterized by common elements with redemption as main theme. For example, the protagonist recognizes a distinguishing gift or status as a child, demonstrates an early sensitivity to suffering, establishes and internalizes a belief system that reflects a moral imperative, a commitment to improving the human condition, develops an ability to transform difficulty into advantage, suffers setbacks but identifies the positive lesson, continues to progress to fulfillment of "inner destiny" with expectations to leave a positive contribution. It is a lifelong work to balance strong needs for power and independence with love and community. He emphasizes that each story represents a life story that can't necessarily be measured against criteria but that each person constructs their story with a similar plot outline. Generative adults visualize their lives in redemptive terms: forgiveness, freedom, fulfillment following periods of pain and suffering. Suffering redeemed gives voice to hopeful and inspiring stories. McAdams does reveal shortcomings in the redemptive story such as an "almost childish" belief to always expect good following the bad. He also argues that redemptive stories reflect our unique American history, beliefs and values. For example, historically we have recognized ourselves as the "chosen people" with a manifest destiny and ambivalence around power/freedom. (McAdams, 2006)

There is an increasing interest in the use of personal stories in healthcare. In fact, many health care professionals recognize story as therapeutic for patients as well as caregivers. (Bowles, 1995; Sandelowski, 1994; Tanner, 1999). Clark explores the use of personal story and what it means to knowing, health and caring in nursing. She notes significance in the way people generate stories in response to illness experience. An

illness story and its telling not only help to identify order and find meaning for the teller, but facilitate growth in self knowledge, a sense of control and healing. She identifies elements of caring in nursing that include: to protect, enhance, preserve humanity and help people find the meaning in illness. These elements of caring are strengthened by listening to personal stories of illness. (Clark, 1995) Similarly, Sandelowski discusses the importance of story in nursing practice with an exploration of the nature of illness narratives, stories that represent patients' efforts to explain and make sense of symptoms, illness and implications for daily life, self image and relationships. The construction of illness stories is based on different elements of the people's biography and the use of narrative models that are based on familiar cultural concepts like lives as "romances, comedies, melodramas or tragedies" in which the individual as the central character chart his or her course. Illness stories are embedded in life stories and are a representation of experience at a moment of time that attempts to impose order and make meaning. As experience and needs change, the illness story will be revised and retold. As patients tell their stories in response to health history elicited by nursing, they offer important information about the onset of symptoms, naming the illness, available treatment, management and likely outcome.

CHAPTER 2

ILLNESS STORIES

I have heard lots of patient stories around the experience of their illness and indeed their stories may have directed outcomes but I wasn't always listening. In the beginning of my case management career, I established discharge plans for individual patients by first reading the medical record which provided clinical information, the initial complaint justifying admission into the hospital along with a history/physical exam, initial results of testing and treatment. Fully equipped with clinical information, I met the patient and conducted an interview to determine an appropriate plan. Although I listened to some of the patient's story of hospitalization, I didn't elicit the patient's illness experience and frankly would not have even recognized it. I was focused more on my own agenda since each patient discharge plan must be documented within a specific time frame. Furthermore, I usually identified the discharge plan before I even spoke with the patient! Not surprisingly, there was occasional conflict over whose plan was most appropriate; my plan or the patient's plan. I often wondered why some patients whom I easily labeled as difficult couldn't simply comply with the reasonable discharge plan that I had recommended. At that time, I lacked the knowledge and skill required to recognize and understand a patient's experience of illness, the meaning for patient and family, the relationship to treatment and management and the impact of illness on daily life. Some patients, for example, with diagnosis of one or more chronic illnesses were repeatedly hospitalized with worsening of symptoms. The descriptive hospital jargon for these

patients is “frequent flyers” who don’t manage their chronic illness well enough to stay home.

Kleinman distinguishes between brief and chronic illness by describing a brief illness as one that may vary in outcome but is generally not disruptive. Diagnosis and treatment are provided and the course is limited in time. For example, my daughter called with complaints of abdominal pain explaining that she had eaten some unusual food on the previous day. She interpreted her symptoms and was convinced by her own story that she had food poisoning. As I listened to her symptoms, I suspected possible appendicitis and urged her to get prompt medical attention. As it turned out, she did seek emergency care, was diagnosed with appendicitis and underwent successful surgery that night and was home next day. In contrast, there is no cure for a chronic illness that takes place over a lifetime and impacts every aspect of life, characterized by remissions or absence of symptoms and exacerbations or increased symptoms.

Although chronic illness affects ninety million people in the United States, which translates to one out of three people or 33%, it is remarkably hidden from our daily lives. (“Prevalence and Incidence of Chronic Illness,” 2007) There are hundreds of types of chronic illness, including familiar diagnoses such as Heart Disease, Diabetes, Stroke, Cancer, Kidney Disease, Multiple Sclerosis and Alzheimer’s disease. People living with chronic illness may not demonstrate untoward symptoms to the public, since symptoms are often invisible, but they live daily with symptoms that cause problems ranging from challenging everyday activities of living to the potential crisis underlying chronic illness. For example, in the story “Fitz Hugh,” Lisa describes her increasing leg weakness and decreasing balance and its impact on her mobility, work and self confidence. (Appendix 2)

The crisis of vision loss is one more assault, a betrayal of her once trusted physicality and becomes a threat to daily life, work, relationships and her self esteem. In addition, the expense of treatment is significant and the coordination between physician office, pharmacy, and insurance company or, in Lisa's experience, the drug company itself is often frustrating and usually exhausting. The treatment of chronic illness requires frequent physician visits, tests, interventions and changes in behavior to comply with treatment. Lisa, for example, not only needed to learn how to administer injections but to carry this out every day. Dr Kleinman eloquently sums up the way people confront these illness problems by writing, "...there is a kind of quiet heroism that comes from meeting these problems and the sentiments they provoke, of getting through each day, of living through the long course with grace and spirit and even humor; sick persons and their families understand the courage even if most others do not." (Kleinman, 1998, p. 45)

The diagnosis, treatment and care of chronic illness can be overwhelming for individuals and families. Dr Kleinman argues that individuals and families create an explanatory model or personal story to organize, communicate and manage symptoms of the illness. Furthermore, the way individuals and families perceive and make sense of symptoms constitutes the meaning of illness. The meaning of illness is influenced by several factors: our personal biography, disposition, relationships, which all occurs in a specific socio-cultural context. The illness story is broad. Kleinman describes illness as how a sick person and members of a family and social network not only make sense of illness but how they manage daily life and respond to symptoms and disability. The manner in which people do this can provide clues to the management of increased/decreased symptoms, treatment compliance and coping with difficulties posed

by the illness. Consider, for example, a research project described the meaning of hypertension held by a group of middle class, college educated men in Seattle who were being treated for hypertension. Many of the participants believed that hypertension was “too much tension” rather than persistent elevated blood pressure. This identification of meaning helped to explain a high rate of noncompliance with medical regimes since individuals were not taking the medication unless they felt tense. (Kleinman, 1988)

In order to appreciate the significance of an illness story and its relationship to care, factors that influence the makeup of illness stories need consideration. Kleinman identifies different levels of meaning in illness: symptoms as meaning, cultural meanings that carry significance to the ill person and personal/social meaning. The interpretation and meaning of symptoms such as leg weakness relies on awareness about our body, our self and the relationship between body and self. Although we recognize the relationship between mind and body, Western culture separates body from thoughts and feelings. Our body is viewed as a distinct entity. Our medical model reinforces this notion by categorizing any emotional/thought process issue impacting treatment as psychiatric requiring separate consultation and treatment. In contrast, Native American culture views body as integrated with mind and spirit so that dysfunction is imbalance or disturbance of harmony. We learn about our body and related activities of daily life such as eating, toileting and bathing in the context of our local culture that influences our ability to identify and express body dysfunction. We understand and predict our body’s function. For example, my sister, Lisa, first complained of left leg weakness causing an ataxic gait that was limiting her ability to walk any distance safely. Although this symptom could arise from a number of problems, such as injury, nerve damage or

neurological condition, my sister interpreted this as likely multiple sclerosis based on her knowledge of her body and self including professional knowledge and experience as an occupational therapist. (Appendix 2) A Native American might interpret a symptom like leg weakness in a broader context reflecting a concept of body around harmonious relationships.

Another level of meaning contributing to illness story construction is cultural meaning or what cultural norms influence an individual's perception of illness experience. This is consistent with Bruner's description of cultural mediation between consciousness and behavior in story makeup. For example, in our culture cancer is a symbolic reminder of unpredictability, uncertainty and unfairness. I met a sixty three year old man who was admitted to the hospital with abdominal pain. He had no prior health issues but was diagnosed with cancer and died, all in a two week period. Cancer directs us to face lack of control and questions regarding risks of environmental pollutants, pharmacology and technology. Kleinman describes individuals as "encased in a visible exoskeleton..." by culturally marked illnesses. (Kleinman, 1998, p. 26) Multiple Sclerosis is a chronic illness that affects vision, mobility and cognitive skills to varying degrees; remissions and exacerbations occur over uncertain time intervals. The cultural meaning is ambiguous since it's not a terminal illness but certain types of Multiple Sclerosis are aggressive with rapid destruction of nerve fibers leading to complete dependence. The prevailing cultural meaning is that MS--while "It could be worse...you don't have cancer"--is a serious, crippling illness that hinders ability over time. Although we have made gains in awareness, understanding and access regarding disabled citizens, our culture prizes youthful, fit and accomplished bodies so that the message about Multiple Sclerosis, the

failure of a sick body, is clearly communicated to the ill person. The cultural message represents a significant contribution to the illness story.

The personal/social level of meaning that contributes to an illness story impacts the response to and management of chronic illness. The illness becomes integrated into someone's life story. Kleinman's imagery is powerful: "Acting like a sponge, illness soaks up personal and social significance from the world of the sick person." (Kleinman, 1988, p. 31) This intimate level of meaning transfers significance from the ill person's life to the illness experience. In order to make sense of the experience of illness, an ill person as well as their family and friends construct an explanation based on the following questions: cause of illness, timing of onset, effect on body, its course, source of remission/exacerbation, control, main effects on life, what is fearful, available treatment and effects. The explanation or story orders the experience to give coherence to events.

The illness story explains the onset of symptoms or how someone got sick. These stories may have multiple versions and Dr Mehl-Madrano, who refers to this as the creation story, notes that, in Western society, the doctor's version of a person's illness story is called the diagnosis. (Mehl-Madrano, 2005, p. 14) The diagnosis is central in our bio-medical model because it predicts indicated treatment, response and overall expectations. The diagnosis even directs financial reimbursement for health care facilities. Health care practitioners elicit the history of someone's "chief complaint" or illness complaint and are charged with interpreting the complaint in the context of patient history and physical findings. Practitioners are influenced by the meaning of patient symptoms as represented in the context of medical practice in culture specific settings. For example, a tissue infection of the upper arms may mean complications of heroin use

or of an injury, depending on the hospital location and local culture. The practitioner recasts the symptom as a disease process or an alteration of a biological system which doesn't take into account the meaning of illness experience by patient and family. The bio-medical model reduces the patient and family experience to pathology. The medical chart becomes the official story and the physician the teller of the patient's story. The patient creation story may not match the physician's version as coded in the diagnosis. Conflicting illness stories will hinder treatment.

An example from my practice about conflicting stories--the patient version and the medical version--can illustrate the problem. An ongoing obstacle to discharge planning is conflict between the patient/family story and the medical model/hospital story of care. Jacqui's story is an example of stumbling blocks to care created by conflicting stories. Jacqui is the long time friend of the patient Steve who had been hospitalized for several days with increasing weakness, difficulty walking and a worsening of colon cancer that had been discovered several months ago. I had not met Steve or Jacqui but understood that Steve's condition had deteriorated, no further treatment was possible, a hospice consult had been completed, confirming end of life and that Jacqui, friend and Health Care Proxy was irate about the whole thing. I was told that she and the attending physician had argued about his condition on the previous day. Although Steve's condition was grave, he was stable for transfer to a nursing facility. So, on one very busy morning, I began the first of many telephone calls to Jacqui in order to establish a discharge plan, likely transfer to a nursing facility for end of life care. Jacqui was recovering from an illness herself and had been unable to even come to the hospital to visit Steve. I looked in on Steve who was lying in bed, jaundiced, somnolent and

whispered unclear responses to questions. It was clear that he was unable to make his own decisions. Jaqui was charged with making all his health care decisions and it was just as clear that she wasn't in agreement with the plan.

We spoke on the telephone. Jacqui spoke softly, clearly and nearly continuously without pause, repeating, "I don't understand...just one week ago we were at the Cancer Center and the doctor said that it was not too late for chemotherapy. I'm getting the run around from people at the hospital...Stevie would not want to give up, would not want Hospice Care...think it's the medication that is making him so weak. I don't understand." As I listened to her story, I pulled up Steve's recent oncology visit/history on the computer screen and incredulously read phrases like: patient disease widespread, patient elected no treatment, missed visits, recent visit to discuss palliative chemotherapy without follow up and an ongoing noncompliance. The medical story did not match up. Rather than interrupt Jacqui's flow, I listened to the rhythm of her concerns, recognized that there was no benefit to go back in time to address nontreatment, noncompliance and lack of follow up. I wondered how to move on. Although I didn't know the meaning of Steve's illness for Jaqui over time, the meaning at that moment seemed muddled. I finally asked Jaqui, "What do you need to know in order to understand what's going on with Steve now?" She paused and quickly listed need to know items including current orders and treatment, medications, testing results including current blood work and the most recent oncologist input. She was reassured that as Steve's health care proxy, her decisions would be respected and carried out. After gathering and providing Jaqui with information including facilitating contact with the oncologist, I waited in the space of uncertainty for her next telephone call. The following day, she called saying that she

understood Steve's condition was serious and that treatment was not available at this time. She agreed to the nursing facility transfer with the understanding that he would be cared for, that he would be medically treated as appropriate and medicated for pain without further disruption of his already altered awareness. At the end of the call, she asked me to "Tell him that I love him and please be sure he gets something to eat, like chicken soup." I returned to Steve's hospital room to pass on Jaqui's message and to let him know the transfer would take place later in the afternoon. He was sitting in a chair, jaundiced, breathing heavily, eyes closed and nodded to my explanation. I wasn't certain that he even understood and I sat by his side not knowing what to do next. At that moment, his nurse's aid picked up the ringing phone and said, "It's the kitchen...what would he like?" "Oh," I remembered. "Send up chicken soup."

The meaning of Jaqui's experience of Steve's illness: worsening symptoms, advanced disease and end of life discussion were not elicited. Health care providers interpreted the medical data, presented the data and became frustrated by what we easily label patient and family denial as well as difficult family with unrealistic expectations. While denial and unrealistic expectations do contribute to miscommunication, they can be more appropriately addressed by getting to the story or meaning of the patient and family's illness experience. Jacqui had an opportunity to tell her story, organize and order the meaning of Steve's illness for her. I listened, acknowledged and made efforts to understand her experience. Empathic listening facilitated my ability to identify the immediate story, understand its meaning, and support a shift in meaning that allowed the discharge plan to move forward with agreement. Stories are reconstructed with changing circumstances, altered consciousness and events.

CHAPTER 3

MEANING SHIFTS/CHANGING STORIES

Changing circumstances and an altered consciousness occurred in my own story about nursing practice. Classes in the Critical and Creative Thinking Program motivated me to reconsider work-related problems. Around this time in my case management career, I started to experiment with a new strategy to establish mutually agreed upon hospital discharge plans by refocusing on what the patient and family wanted to do. What a concept!

Rather than imposing my plan at the onset, I solicited the patient's plan which usually was to go directly home. We discussed necessary criteria for the home plan that would include, for example, recognizing that managing independently at home means independent walking, stair climbing and adequate strength and ability to care for oneself throughout the day. A prolonged hospitalization which is measured these days by a stay over four to five days impacts someone's ability to be up and around quickly. When a patient's hospital course altered the initial discharge plan, the patient and I would reevaluate discharge plans by reviewing criteria for home care that the patient had previously identified. Generally, patients who were unable to safely return directly home would recognize the obstacles by themselves and be receptive to alternative planning. It sounds so simple but at that time it seemed extraordinary to me. Although I still didn't know about the significance of illness story at that time, I was impressed by patients' ability to shift attitude, expectation and behavior.

Since the meaning of someone's illness experience influences behavior, emotional and cognitive states, it's possible that meaning moved or shifted in a positive manner promotes healthful story reconstruction. How does this work? A research project conducted to examine meaning shifts in patients participating in wellness acupuncture analyzed three hundred and sixty seven letters written by patients to describe personal outcomes, expectations and patient-provider relationships. The letters were personal stories defined in the study as "first-person accounts by respondents of their experience." (Stibich & Wisslow, 2006, p. 1) which is consistent with illness story description in my paper. The illness story is noted as the point of access to patients' meaning of illness. Although the study doesn't specifically identify types of chronic illness, the study respondents suffered some kind of chronic illness, sought additional therapy in acupuncture or had exhausted conventional medical therapy. The study analyzed meaning shifts that were coded and sorted into themes. (Stibich & Wisslow, 2006)

The study results reveal five major themes and possible models that help to appreciate and further understand the significance of illness story, meaning and promoting positive change in meaning. The meaning shift themes include: from a patient goal of curing the illness to improving health, with respondents describing increased recognition of the mind-body connection, increased benefit of responding to physical/body changes, and modifying behavior around physical activity, rest, relaxation and diet. A second meaning shift theme is focused on interpretation of symptoms: from symptoms as problems to symptoms as teachers, with respondents describing new insight into symptoms, becoming aware of patterns such as the physical elements of anxiety, learning from patterns, reflecting on the way behavior, attitude and relationships affect

body/symptoms and making changes. The shift themes from healing as passive to healing as active and from being dominated by illness to moving beyond illness are focused on sense of control/mastery of symptom problems. Respondents describe participation in care rather than being passive recipients of treatment. (Stibich & Wisslow, 2006) This reflects both Donna and Lisa's stories. (Appendices 1, 2) There is a sense of empowerment and willingness to "heal thyself." The last meaning shift is from recognizing the practitioner as technician to recognizing the practitioner as healer. The responder perceives the practitioner as caring, empathic, and nonjudgmental.

The meaning shift themes are examples of reframing the illness experience and story to promote changes in patient goals, patient role, and in the stance to illness and the therapeutic relationship. The reframing of the story underlies the positive outcomes in this study. The research group presented possible meaning making models to support the rationale for changes. Although each has merit, the "Meaning Model" warrants closer attention because it proposes that a change of meaning produces physiological changes. This is similar to Kleinman's study of illness stories, specifically his explanatory model that describes the framework from which patients construct illness story that influences treatment, management and the worsening or remission of symptoms. The Meaning Model says there are three main factors that bring about meaning changes: the explanation of illness and treatment must make sense to the patient, the patient must feel care and concern from practitioner and the patient must feel a sense of control/mastery over the illness. Data from the letters in the study support this model. Interestingly, there hasn't been a direct study of this model to date. (Stibich & Wisslow, 2006)

Another look from the meaning model in reference to Jacqui's story is helpful to understand just what factors contributed to the meaning shifts. As noted earlier, she had an opportunity to tell her story without interruption so that she reorganized her experience, reframed the story with a coherent meaning that made sense to her and demonstrated some control over the process. Compared to her experience of disagreement with Steve's physician the previous day, our shared experience was more helpful. After reassuring Jacqui that I would speak to the oncologist, I managed to find him, discuss the current conflicts and arranged for Jacqui to call his office at a specific time to actually speak with him. It's of interest that she didn't even attempt to call him, which may just be further evidence of not following up on recommendations. An alternative explanation to this is that our discussion was sufficient and answered her questions. I can only suggest how her shift of meaning occurred but her telephone call surely demonstrated a new story.

Women reframe their story of living with multiple sclerosis in another exploratory study of the relationships among persons, symbolic meanings of illness and their occupations. (Wright-St Clair, 2003) Fifty one women, whose age ranged from thirty to fifty years old, participated in interviews around topics of their illness. The data showed two different sets. One narrative theme described a search for cause and for meaning in uncertainty characterized by the metaphors of battle engagement and loss of self. In contrast, the other narrative theme described transformation of self and illness characterized by metaphorical images of harmony and empowerment. Data analysis identified five symbolic codes for women's interpretations of living with MS: aggressor,

savior, partner, guest and adversary. For example, one woman spoke about life with MS as

Like living in the twilight zone. You sort of keep it at bay...but it is like having the crew of the Marie Celeste in your hot water cupboard. This is what is like, that is exactly what it is like. Who knows when they pop out and see you. (Wright-St Clair, 2003, p. 50)

A social interactionist theory was used to interpret data. The theory rests on three premises: people act toward things on the basis of meanings held for them, meanings come from interaction with people and things and these meanings are processed, framed and reframed through a subjective interpretation. (Wright-St Clair, 2003) The participants in the study expressed new insight and understanding of their illness, management and impact on daily life following the research project. As the women told their story, they explored areas not previously talked about and, in fact, some women had never talked about their illness before the project. Their stories demonstrated a shift of meaning from loss to control/mastery of illness in their lives. They used the powerful metaphors to make and express meaning.

Stories make sense of illness but only if they are told. Although the stories in the previous studies provide data that illuminates the process of story construction and reconstruction, stories are to be shared. Arthur Frank, author of The Wounded Storyteller, urges that stories must be told to facilitate a shift in the dominant cultural meaning of illness from passive, “victim of illness” who becomes a “recipient of care” to an active participant engaged with care. (Frank, 1995, p. xi) He believes that people constructing illness stories must reclaim their voice, tell their story not only to make sense for themselves but to teach others: “Ill people’s storytelling is informed by a sense of

responsibility to the commonsense world....they seek not to provide a map that can guide others-each must create his own-but rather to witness the experience of reconstructing one's own map...storytelling is for an other just as much as it is for oneself." (Frank, 1995, p. 17) The relationship of storytelling is reciprocal and the story space is for both the teller who shares the illness story, constructs and knows the meaning of illness, as well as for the listener who embraces the story. The story not only becomes a point of access for meaning for the listener, recognition and understanding of illness meaning with its accompanying loss, pain and suffering, but it becomes an opportunity for transformation. For example, following my initial conversation with Jacqui about my patient Steve's condition, I was moved by her confusion, concern and impending loss. I was pulled up by memories of my own loss, was able to sit and be with Steve rather than do for him. There are opportunities for change, growth and transformation in the space of storytelling for both teller and listener.

Stories of illness are like maps that guide the ill person in the care and treatment of a chronic illness over a lifetime. They are a valuable tool for health care practitioners, too. We need to ask for our patients' illness stories, foster an environment that encourages and supports the necessary space, time and resources, recognize and respect the significance of an illness story to patient care and to our own growth and development as human beings. The significance to care can't be overstated. The patient is the main character rather than the medical team. The patient story represents meaning that impacts the treatment, the rise and fall of symptoms and the course of illness. Recognizing and knowing the story provides an opportunity for health care providers to

collaborate with patients to shift meaning toward well being. Maps can direct us to a new place that does provide space, time and resources for sharing story.

The challenge of locating this space in our current health care system is daunting. In the past twenty years, our health care system has become increasingly complex and fragmented with reliance on technology and pharmacology. Health insurance companies determine payment based on “level of care” which is interpreted by criteria categorized by body systems, lab and imaging values and hospital treatment. One of my responsibilities as a nurse case manager is to act as a liaison between the hospital and specific insurance payers and includes calling with clinical information to justify each day of hospital care.

There are specialists for each body system including the newest member called the “hospitalist” who treats only hospitalized patients. This specialty relationship with the hospital is based on a contractual agreement between physician groups and hospitals. Although there are advantages to having the hospitalist available throughout the hospital day, the primary care physician who knows the patient is not involved in hospital care. Charon describes clinical relationships as “starved of time, dignity and regard.” (Charon, 2004, p. 5) Not long ago, I overheard an exchange between a patient and one of her physicians. She was lying on a stretcher in the hallway just about to be transported to radiology. He asked how she was and she answered that she was concerned about her belly pain. He responded that he was only there for her breathing and asked her to tell him “just about your breathing.” Not only do patients surrender their story but need to determine and direct complaints to appropriate specialists!

CHAPTER 4

HONORING STORIES/IMPLICATION FOR PRACTICE

My current nursing practice has been enhanced by drawing out and listening to patient's stories of illness; the point of access to the current meaning of illness during hospitalization. As I interview a patient, I note that my interview has become our dialogue. My practice, coordination of care, has become a collaborative act. For example, an elderly woman was hospitalized with an exacerbation of chronic obstructive pulmonary disease, had been treated, improved and was stable for discharge home with home care services. On the day of discharge, the patient suddenly felt unable to go home. I asked her what had happened to change her plan. She spoke at length. I listened and tried to identify the story threads. Initially, it was difficult and I couldn't recognize the direction. Finally, I repeated back what I thought I had heard her say, asking her if she had meant she was anxious about being alone. "No, that's not what I mean!" she emphatically replied. I continued to listen and heard her say that she was uncertain about whether she would "get better," improve so that she could resume driving and get out regularly. In addition, she described how difficult it was for her to ask for help at home, i.e. grocery shopping and errands.

With an understanding of this woman's experience of illness as represented in her story, I facilitated additional referrals to the home care agency. As she told her story, she began to make sense of her current hospitalization. Although it was hard not to interrupt or hurry her along, I continued to listen and recognized that she was organizing her experience to find the current meaning in relationship to the discharge plan. For

example, she used phrases like, “I have trouble with my breathing...but my daughter is helpful...able to walk without help...don’t want to go to nursing facility.” When she finished her telling, she looked at me and announced, “I’ll be ok to go home.” The illness story told helps individuals to find meaning that directs behavior and expectations. The illness story received helps practitioners to understand the meaning of an illness experience and its relationship to care so that care can be provided in an appropriate and effective manner. In addition, I am moved, inspired and enriched by my patients’ stories. I have come to see listening to/receiving an individual’s story of illness as a distinct privilege. Rita Charon, physician and recognized authority in narrative medicine writes eloquently about listening to her patients’ stories;

“I find tremendous interest and joy in allowing myself to be bathed in a stranger’s telling of self. I am stunned at how singular-how absolutely unique-are these self/body narratings. It is a charged experience for us both...” (Charon, 2004, p.188)

Although I’m unable to take this time with all my patients, I am prioritizing my time so that I can practice in a storied manner with some patients. My nursing practice has changed from taking information from patients and imposing reasonable discharge plans to receiving, listening to patients’ stories, experience of illness, with a collaboration in discharge planning. My next step in nursing case management is the establishment of my private practice, Tour Guides for Health, a private care management company. My practice will be distinguished by the use of story: health history in the context of life-story, illness story and explanatory mode of illness. Kleinman describes this as a way “...to borrow from the biographer’s and historian’s craft.” (Kleinman, 1998, p. 237). Illness problems with specific patient/family goals of care will be identified with an

appropriate plan of care. Empathetic listening, translation and interpretation are necessary skills to collaborate with patients and families to negotiate their story of illness through the health care system.

The mission statement of Tour Guides for Health is a work in progress. At present it is to provide coordination of health care for individuals based on their meaning of illness in a way that promotes an individual/family's well being. This includes assessment based on eliciting/listening to the history as noted, identification of illness problems (for example, leg weakness limiting physical activity and fear of losing a job) and a plan of care to address problems. The services range from community referrals to assistance with medical providers, medications and safely living at home. Care coordination would take place across the continuum of health care.

Although our health care system is complex and often confusing to the novice tour guide, I am an expert in this area. I first became aware of my expert status during my Cognitive Psychology class. After completing an assignment focused on novice/expert problem solving, I recognized that my knowledge and skills over twelve years constitute firm ground for new ventures. I have had the opportunity to work as a case manager in various settings: a hospital-physician group, skilled nursing and rehabilitation settings, a multi-specialty physician group, a hospital and home care. I have a broad knowledge of the health care system, levels of care, primary care practice and insurance reimbursement. I have a wealth of experience in caring for individuals and families, understand the importance of therapeutic relationships, recognize effective strategies and am willing to experiment with new models. For example, as I have researched illness stories, I have practiced receiving patient stories at work. In addition, I

have established relationships with significant practitioners in the North Shore area. I'm prepared to reorient my nursing practice outside the institutional walls with a commitment to a "meaning centered model" of care. (Kleinman, 1998, p. 252)

The need is based on an understanding that we are living longer, chronic illness is on the rise and very often care givers live a distance making attendance to care difficult. I have recently spoken with a nurse who started her own case management company associated with her former employer MGH so that I know that name recognition facilitates referrals. Her referrals are increasing so that she needs more staff. The web site MGH PrimeCare describes Elder Care Services and how the services are carried out. Not surprisingly, individual stories about people's problems that have been solved by the program are woven throughout the site.

As Tour Guides for Health takes shape, another use for illness stories can be found in "Health Talk Connection" which is a concept borrowed from the popular public radio talk show called "Car Talk". I imagine co-hosting a radio show that is informative as well as entertaining. Although health issues are not amusing, there is a certain perspective that illuminates with humor. Adult children who live a long distance away and visit aging parents infrequently may be perplexed to discover changes in parent health issues that require action. For example, what to do when an aging parent starts to demonstrate short term memory loss and difficulty with managing daily activities at home? The radio show provides a format for presenting a specific topic, for example, memory loss, with discussion of courses of action and how to access available resources. People would call in with questions and co-hosts would respond and illustrate points with

stories of similar situations. Tune in to “Health Care Connection.” A demonstration tape is in the works.

There are opportunities to educate nurses about the significance of illness stories in daily practice in various settings: physician office, home care, skilled nursing and rehabilitation facility, hospital and nursing home. I want to establish an educational workshop to teach about illness stories. This will be a collaborative effort with LANES (League for Advancement of New England Storytellers). The organization supports story telling and related activities and offers an annual conference in the spring. I’ve shared some ideas with other members who are aware of the untapped potential of nursing participation in the organization. Nurses must earn continuing education units to maintain professional licensure, which could be accomplished by attending “Illness Story” workshops. In addition, LANES has an opportunity to reach outside the traditional story telling membership and extend membership to nurses.

LANES workshop, radio talk show and private practice make up my next steps or chapters in my own story. I have a lot to do. After a pause, I stop to reflect on my values, beliefs and interests. I am taking risks to move my practice to a place congruent with my best personal and professional self. Based on my research and experience, I believe that illness stories are an individual’s perception of experience and represent meaning. Illness stories are broad and include family/friends interpretations in the setting of specific socio-cultural norms. Individuals make sense of their illness by telling their story. Stories change over time and circumstances but must always make sense to the teller. Tellers need listeners. The relationship between teller and listener is mutually beneficial. Attentive listening to an illness story, that point of access to meaning,

facilitates improved care, reduces conflict and bears witness to another's plight. We are moved to action.

I value the contribution that each person's illness story brings to care, the unique experience of illness that speaks of complexity, relationships and cultural input. Meaning-centered care provides a balance to current practice; places the ill person in the center of care and promotes collaborative care among an ill person and health care practitioners. Both ill person and practitioners are engaged and empowered. Care organized around meaning encourages more humanizing care rather than the current standardized care. Reflecting on the care of chronically ill persons, Kleinman writes, "Care is a constant struggle to experiment and persevere-like the illness experience itself. (Kleinman, 1998, p. 249)

As I continue to experiment with strategies in my nursing care, I recognize what seems to me an amazing progression from my disheartened state three years ago, a time when my patients' stories blurred into one long story called futility, to early and uncertain changes based on reexamination of personal/professional self fueled by my learning experience in Critical and Creative Thinking classes, to finally a reorientation of practice around a model that makes sense to me. As I look forward to change in the future, I take stock by always saving room for reflection, balancing uncertainty with confidence, seeking support, remaining open and receptive and knowing when to rest. Indeed, my project is about movement from recognizing the significance of illness stories to planning a storied practice, from my days of discouragement to my present that is characterized by hope and renewal.

APPENDIX 1

DONNA'S STORY

GOING TO THE WELL

It all started with routine blood work. The results showed a mild anemia that meant another blood test. It was no cause for concern. Donna, who worked as a nurse case manager at a Boston rehabilitation hospital, took the telephone call that came one morning at work in the privacy of the stairwell. It was alarming as the nurse said, "Donna, there is something wrong with your blood test. Get a piece of paper and write this down!" Donna's mind raced around; "something is wrong" and "get a piece of paper" or was it "get a piece of paper" and "nothing will be wrong" or "get a piece of paper" and "take what down." Donna held the stair rail tightly with no paper in sight, her heart pounding and simply said, "Just tell me." She heard a flow of unfamiliar technical terms like antibodies, spikes and monochromal in the midst of a clear message; there are "abnormalities in your blood test and you need to see a hematologist for further testing." With that, Donna went straight to "Oh my God, what if I have cancer" and her anxiety rose like the oppressive heat on that summer's day. She managed to see a hematologist that very day and endured a bone biopsy only by singing her way throughout the procedure. It was the first ever singing biopsy carried out in that office. Although the hematologist didn't say cancer, he expressed concern about the blood abnormalities so that cancer could not be ruled out. Then the waiting, waiting for results; those were the hardest days with so many concerns about "something is wrong", "how can something be wrong with me?" I don't want something to be wrong. The call came again early one morning at work. The doctor said, "Are you sure

you want to hear this news over the telephone?” What could she say? What would you say?

Donna steadied herself to hear the bad news over the telephone. The doctor quickly explained, gave it a name and called it Chronic Lymphocytic Lymphoma, a type of cancer, cells in the bone marrow, a chronic illness with no cure and possible treatment in five to ten years. It sounded ominous. She asked for a follow up appointment to which the doctor replied, “But, what for?” With that, Donna quickly arranged for a second opinion and bought a new shower curtain.

The oncologist at the Boston hospital provided the second opinion and spoke of “unusual characteristics” in the pathology but was unable to answer her questions. He did, however, quickly refer her to a social worker for her anxiety. Apparently, Donna raised her voice with concern. Donna sought out a third opinion for information and help that hadn’t seemed forthcoming to date. The next Boston oncologist spent over an hour with Donna and her husband answering questions and offering patient explanations. CLL is one type of lymphoma; there are hundreds and some are worse; there is no cure; maybe treatment in five years. He offered counseling and gave her permission not to be cheerful. Apparently, her husband had urged Donna to seek support from a neighbor who lives with breast cancer and seems to do it in perpetual good humor. “Donna will need to figure out how to live with this,” the doctor advised. How would she make sense of “why me” and what could she do about it. Her first decision was to change her care from her first doctor, the hematologist whose office felt less like cancer, to the Boston oncologist specializing in lymphoma, a first step in making it real.

She felt the need to “do something” and to begin to make some sense of this illness. After all, she was not experiencing any symptoms except the devastating disruption of life

as she had known it and its accompanying fear, uncertainty and anxiety. Friends, family and colleagues gathered around Donna and offered lots of advice: acupuncture, spiritual healer, medical psychologist, Yoga, meditation, bio-feedback, hypnosis and don't forget exercise. And so she lined up her helpers and started. Her first helper, the acupuncturist started treatment and told her peacefully that "We only have this moment and in this moment we are healthy." But, what about all the other moments? He recommended "a healing shield" to protect her from negative people, places and things. Naturally, he would contribute to this "healing shield" during treatment but urged her to look for her own shield. After several treatments, Donna felt better and actively engaged in promoting her health or as she also described it as a way to "ward off the devil...the cancer devil...what do I have to do?" Meanwhile, the inner dialogue in her head is raging "Why do I have fucking cancer?" but she doesn't want to miss anything and wants to listen without hostility so she pulls in an occasional pharmacological helper at times prescribed by her doctor who urges that "you don't have to white-knuckle it."

Her next helper, the medical psychologist offers another spin one morning at 6 am just before commuting to work. He confirms what Donna already knows, "you have been hit by a hurricane with this diagnosis." He wants to help Donna, who he describes, who everybody knows, as "resilient, vibrant and high functioning," to right herself once again. He talks about the mind-body connection explaining, that the mind thinks and the body interprets and acts like a canvas that "paints the symptoms." It all sounds intriguing, even helpful. But she is still "fucking pissed off" that she has cancer. She bristles as some friends urge her to seek the lesson of lymphoma. She was doing perfectly fine without it! She bargains and magically thinks that if she does good work every day, she will be

rewarded with a miracle cure. She bargains and is almost grateful that she doesn't have a stroke, Parkinson's, leg amputations or any of the horrible problems held by her patients. But she does have cancer and is beginning to say it out loud. But it feels bad: she is bad, ashamed and almost dirty, bears a Scarlet C for cancer, has bad karma and it's a bad omen. She doesn't want it and schemes to give it back somehow. How can a rising star/talk show host and recent joyologist have cancer? She hears the words cancer/no cure and that it sits in her bone marrow, the very core of her being. She doesn't want to die. How can she make peace with this? She wants to be in the space where her 21 year old daughter can casually ask, "So mom, how is the lymphoma going?"

Donna searched the internet for miracles and discovered a healing vortex just north of Santa Fe. She and her two best friends traveled to Santa Fe late in that fall. Not long after their arrival they set out one warm, bright afternoon to visit El Santuario de Chimayo. It was a perfect day for a miracle. The story of Chimayo is intriguing; a shrine was built in 1814 after Don Bernardo Abeyta, a parishioner from a nearby church, saw a bright light shooting up from one of the nearby slopes of the hills near the Santa Cruz River. He went to the spot and noticed that the shining light was coming from the ground and he began to dig and to his amazement found a Crucifix. This Crucifix was brought back to his church but disappeared only to be found again in its original spot by the river. This occurred three times before the parishioners understood that the Crucifix wanted to remain in Chimayo and a chapel was built. Then the healings began and over time, the chapel has become known as the "Lourdes of America," with hundreds of thousands of visitors coming each year to worship and seek cures for all sorts of ailments. No one knows how this came about but there are testimonies that the extraordinary healings occurred as far back as 1814.

Legend holds that the soil from surrounding hills is blessed and the source of healings. All visitors are welcome to scoop a small shovel of “holy dirt” from a little well adjacent to the chapel.

And so it was, Donna and her friends entered the chapel and went straight to the prayer room, narrow room, dimly lit with discarded braces and crutches in the corner, before/after healing photographs of infants, children and families and primitive looking handmade shrines. There was muffled giggling in the corner. It was strange; there was a surreal quality to the room. They continued on to the El Posito, the little well and took a small scoop of damp reddish dirt from the hole and into a zip locked baggie. They solemnly walked from the prayer room, through the chapel and paused to read about extraordinary testimonies recorded on a visitor brochure. There were stories of healing, recovery and spiritual enlightenment and on the last line someone was quoted as saying, “It did not cure me but ... sometimes peace of mind is better.” Donna held her bag of sacred dirt, gestured to the line and frowned. She and friends wandered to the center of town and waited for some sign that the holy dirt had begun a miraculous healing, like the heavens opening up with a clear directive or like the surrounding hills speaking in chorus.

Nothing happened. There was no sign. The friends quietly separated and continued to shop for healing icons. Then, a remarkable event occurred as Donna was stopped by an exotic looking woman dressed completely in black named Dona, recovered alcoholic and cocaine addict whose self declared mission was to pass out small stones inscribed with the word HOPE. She took a stone from her basket and placed it in Donna’s hand. Donna told her that she had cancer and Dona immediately took hold of her hands and began to pray out loud right there in the middle of the street...”In Jesus’ name cast off cancer in your

body...you are strong, hopeful and healthy...In Jesus' name! Amen!" And with that, Dona took her basket of stones and disappeared down the quiet street.

Donna and friends returned to their hotel. Donna confessed that she had returned to the sacred dirt pit wondering, "what's up with this holy dirt...is it a continuous source of dirt from the earth's core or what?...Is this a scam?" She learned that the dirt is brought in from the surrounding hills, is blessed and placed in the well. She also admitted to feeling rather irritated by the plastic flowers scattered throughout the prayer room. She pulled out her newly purchased Bob Marley book, a souvenir for her teenage son, to his lyrics: "open your eyes, look within, are you satisfied with your life?" Hmmm? Was it a sign of sorts?

The friends prepared to fly home laden with healing candles, small shrines, and bags of holy dirt. Although Donna felt somewhat disappointed with the seeming lack of response to the blessed soil of Chimayo, she announced that her search for a lymphoma cure was now over. She would let it unfold. She was beginning to make a least a truce with her diagnosis, this lymphoma. Although she felt an urgency to get on with her life, she understood that she needed to learn how to come to terms with the uncertainty and overwhelming anxiety that followed this illness. She didn't want to be afraid anymore. Once again, she heard Bob Marley's lyrics, "open your eyes look within, are you satisfied with your life?" Oh...she was beginning to see, maybe all that she needed she already had. She looked over at her friends who had traveled so far with her. She realized that they had helped her to look for, to find and to know hope, strength and courage. And that is the real miracle of Chimayo.

THE END

APPENDIX 2

LISA'S STORY

FITZ HUGH LANE'S CRUTCHES

The summer of 2002 my summer job took me to the beautiful Gloucester Harbor where I sold "Harbor Tour" tickets out of a little ticket booth for an alcoholic businessman. I often wrote to keep my self occupied. There is a funny message someone left me and it says, "I'm reading your brochure on Harbor Tours and it says: *Private Charters, Business Outings, Fishing Trips and Burials at Sea...* I'm just wondering... The burials at sea. Do you have to be dead for that?" I liked that message, so I saved it. Two lovely rugged and handsome fishermen came by; they're always friendly and will sit down and talk. They'll give compliments and flirt with me and wait for me to say, "Yes, I'm an Escort service, this is really an escort business and I'll do what ever you want." But, I never say that and they eventually get on their way. And so life goes on; in the shadow of Fitz Hugh Lane whose tall stone house sits above me on Tuck's Hill. Ever present safe haven and public restroom. It is a nice park and on lonely days I'll go up and see his statue and read the word he left for visitors to see. Alongside his statue are his sandals for which he invites passers by to stand in and recognize their own dreams as did he, all those years ago. Fitz Hugh Lane has captured my heart; whenever I feel sad and blue I remember that he was here, an artist capturing Gloucester's early fishing history. Telling the colorful and interesting stories of Cape Ann's past with his paintbrushes. I'm struck by his persistence in living his dreams, for by his statue by his seated figure are his crutches. Fitz Hugh Lane had a physical disability which left him to depend on crutches to get around. I hear stories of how he would go out to Ten Pound Island by boat to spend the day painting his canvases with the images that he is so famous for. He was such an inspiration! Gloucester, city of light.... These words would hauntingly find me a few years later when my own darkness seemed too much to bear and was in great need of light.

Summer turned to fall and the Thanksgiving holiday was approaching. Autumn was busy, filled with brisk colors and the crackly cool feel of the changing season. All of a sudden I experienced an occurrence of double vision. It was freaky. Two of everything! I had to cover one eye so I could drive. Everything was blurry. I would reach for things and miss completely. I was trying to be brave, but also in a complete state of denial. I felt like I was hiding, trying to mask these strange symptoms.

My doctor, at the time, sent me to an optometrist. The optometrist thought that I was experiencing the stress of finishing my college degree. All that late night studying and reading combined with middle age was catching up to me. After all, everyone experiences vision changes as they get older. Don't they? I was given a Brocks string to strengthen and practice visual convergence. Weeks went by, I then was thinking, that middle age would also explain my balance problems. And maybe it would explain my left foot dragging, causing me to trip when I would take a long walk. What about that strange tightness in my left leg that I could not stretch out. I was extremely fearful of some invisible something, that I could not explain and did not know. If I had, what I thought I had, there was no cure. "Don't think like that!" I'd tell myself.

I didn't have health insurance. I was going to graduate and move back to Montana, see my kids, start my career, buy a house, get married some day. My list went on.

Four years went by. The symptoms came and went, but mostly they lingered. And I got used to it, after all what could I do? Then came a time where I could deny it no longer. I had trouble making the steep stairs at my house. I was on the floor at my skilled nursing facility job and was becoming overly hot and exhausted. If I continued, I staggered as I walked. This is dangerous I thought, I made excuses to my patients, and finished up. I hid from the staff. I rested in a chair and felt my way down the hallway using the walls as support. I went out to my car and wept. I felt so alone. I made a doctor appointment.

My doctor was actually my nurse practitioner. Knowing I had no health insurance, she referred me to a local non profit physician help group. I had directions to the church where this help was offered, on a certain day, at a certain time. I was instructed to make sure to be early and be sure to be in line first because it was "first come first serve.", and

sometimes there was a bit of a wait. I could not stand for long periods of time. Would all the chairs be taken? Would someone come with me? I was terrified. It ended up that my boss, my friend and mentor came with me. She knew the people at the Shepherds Hand Clinic and helped me get registered. I waited. I was treated with respect. I waited at a table with other people who were low income and without health insurance. Some had health insurance but needed some other kind of assistance with their expensive prescriptions. While the “intake” volunteers took my information, I held my head in my hands. So discouraged, what was happening to me? All kinds of people and families with small children were there. I kept thinking to myself, this is America not some third world country. At the time President Bush was having his second world’s most expensive inauguration. I was so angry, but if I thought about it too much I’d hardly be able to walk. I knew that much about living with MS. Did I say MS? I did, that is what I thought I had. I remembered what it was like to have health insurance and to walk into a clinic with confidence and ease. You’d be seen by your Physician, chat, come out with a prescription for your flu and be done with it. God only knew what was ahead of me. How would I pay for all of this? It was such a dark and ominous time. Like some kind of monstrous black storm cloud and rogue ocean wave and wind, all at one time, ripping with giant claws into and swallowing a tiny little sail boat that was me. That day, I faced great uncertainty and darkness. I left with an appointment to see an ophthalmologist and a neurologist. More fear.

The good news was that this Shepherds Hand Clinic would pay for all of this. I was so greatly relieved. Even though I knew what my invisible enemy was, my denial was stronger. Each time I heard the words, “might be”, “could be, MS”, it was like a fresh slap in the face and I would be stunned. I’d go out to my car and cry. I remember the neurologist asking me what I thought I had after the initial examination. I wasn’t able to walk heel to toe amongst other things. I failed. I cringed. I shut my eyes. I actually said the word, MS, except it was more like I whispered those words. Inside I was screaming. One Lyme Tick disease blood test and MRI later, the neurologist confirmed my diagnosis. I again wept, especially when I saw pictures of my brain with the classic white places that show up on the MRI. “My brain is sick”, I mumbled. To this day pictures of MS brains are difficult to look at, no matter who they belong to.

I had no clue what to do. How do I accept this? What the hell was I going to do? I held my head in my hands. I'm single. I could not do one of my jobs. I hurt. I was scared.

Then came my SOL phase. Shit out of luck acceptance phase. I thought this diagnosis was the absolute number one, worst, most awful, end of the world thing that could happen to a person. I sat at my kitchen table with my head in my hands and sobbed for 4 days, what was I going to do? My neurologist was extremely helpful suggesting how to apply for Social Security Disability, since I would no longer be working at the Skilled Nursing Facility, and giving me the phone numbers of the drug companies that offered expensive MS drugs at a low income price. This disease I learned is very expensive. How about \$10,000 and up per year and that is a low estimate. Meanwhile just telling people what my diagnosis was an experience in itself. One receives all kinds of responses. One would have to prepare the recipient of such news before hand. One would be met with their own denial. "The doctors were wrong," "Just be glad it isn't cancer," or "My friend has that, she takes a shot and is on a special diet, she's fine." Then there was the tidal wave of nutritional supplements that would cure me Fill in the blank. Blah, Blah, Blah, Blah, Blah, Blah- Blah. Nothing anyone could say was in the least bit comforting or helpful. I was devastated.

I turned to my faith. I begged God for answers. And in the still moments of holding my head in my hands, alone, I found solace and comfort. Remember nothing anyone could say or do would or could help me but somehow God came through. And I had quite the attitude. By the way, I hated God. He did this to me. *No, No God doesn't give diseases.* I felt so bad about being on disability, taking hand outs was not something I felt good about. Plus I would have to wait 4 months at least for Social Security Disability to make a decision. Plenty of time to, to, to,... to notify all my creditors and apply for food stamps assistance. Did I really say that? NIGHTMARE. I felt God's spirit taking to me. *Didn't I know that all the world's wealth belongs to Him? Didn't I know that we are all equal, rich or poor? Try telling that to people you owe money to? Didn't I know He'd get me through this somehow? Didn't I? There are plenty of Bible stories that are stories of shit out of luck people and somehow they make it. Happy*

Ending stories. You don't have all the answer now but you'll make it and see how I'll provide for you. Step by step, step by step.

Well it has been 4 years since I've been riding out this whole MS ride. I certainly have been through a lot but I'm also learning a lot too. I'm a whole different person now. The first drug I was on made me so sick. Then I had a relapse and lost the vision in one eye. Yikes! Now I'm on this great drug that I inject every day with minimal side effects. I'm actually much better than I was, as this drug is preventing relapses. Constantly evolving and changing. It is not the end of the world! I'm reinventing myself, discarding what doesn't work and holding lightly on to what does work. The meaning and purpose I've found is that in my story I have found out that I'm an incredibly strong and resourceful woman. A gift. Along the way I'm finding out how to turn my enemy into a friend and make it work for me. And it is working for me. I get to put my own health needs first. Prioritize. I'm more compassionate. I'm way more myself and what God has called me to be. I know what others who have some invisible or unseen disability know and if they don't I can help them know as others have done for me. I laugh more. I've learned to do things differently. I may not be able to hike like I used to but now I have a horse, and she is my round trip into the woods and mountains. I exercise with a cooling vest and swim laps in a pool. I listen to myself better now. I have a job that I do and I'm so fortunate to be able to do it. I have a better understanding of gratitude, and I know that I must live every day. The other wonderful thing is I'm not alone. I have that God I love to hate and I have many people that have chosen to help me along my way. I think when I hear other's stories like Fitz Hugh Lane it gives me strength and I hear the whisper of living your dreams. When I hear my own story I know I have to make the dream happy.

~

Lisa LaChance~

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